



2005

# Guide for Early Intervention with Multiple Sclerosis Patients

Anni Stafford  
*University of North Dakota*

Follow this and additional works at: <https://commons.und.edu/ot-grad>



Part of the [Occupational Therapy Commons](#)

---

## Recommended Citation

Stafford, Anni, "Guide for Early Intervention with Multiple Sclerosis Patients" (2005). *Occupational Therapy Capstones*. 307.  
<https://commons.und.edu/ot-grad/307>

This Scholarly Project is brought to you for free and open access by the Department of Occupational Therapy at UND Scholarly Commons. It has been accepted for inclusion in Occupational Therapy Capstones by an authorized administrator of UND Scholarly Commons. For more information, please contact [zeineb.yousif@library.und.edu](mailto:zeineb.yousif@library.und.edu).

# GUIDE FOR EARLY INTERVENTION WITH MULTIPLE SCLEROSIS PATIENTS

by

Anni Stafford

Advisor: Deb Byram

A Scholarly Project

Submitted to the Occupational Therapy Department

of the

University of North Dakota

In partial fulfillment of the requirements

for the degree of

Master in Occupational Therapy

Grand Forks, North Dakota

May  
2005





## APPROVAL

This scholarly project, submitted by Anni Stafford in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

Debra J. Byrum, MA, OTR  
Faculty Advisor

5-5-05  
Date



## PERMISSION

Title                      Guide for Early Intervention with Multiple Sclerosis Patients  
Department              Occupational Therapy  
Degree                    Master's Occupational Therapy

In presenting this Scholarly Project in partial fulfillment of the requirements for a graduate degree from the University of North Dakota, I agree that the Department of Occupational Therapy shall make it freely available for inspection. I further agree that permission for extensive copying for scholarly purposes may be granted by the professor who supervised my work or, in her absence, by the Chairperson of the Department. It is understood that any copying or publication or other use of this Scholarly Project or part thereof for financial gain shall not be allowed without my written permission. It is also understood that due recognition shall be given to me and the University of North Dakota in any scholarly use which may be made of any material in my Scholarly Project Report.

Signature \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_

## TABLE OF CONTENTS

### CHAPTER

I.	INTRODUCTION.....	7
II.	REVIEW OF LITERATURE	
	Description of Multiple Sclerosis.....	9
	Etiology and Epidemiology .....	9
	Types of Multiple Sclerosis.....	10
	Diagnosing Multiple Sclerosis.....	11
	Course and Prognosis of Multiple Sclerosis .....	13
	Clinical Signs and Symptoms .....	14
	The Most Commonly Reported Symptoms .....	14
	Symptoms Exacerbation.....	16
	Intervention Strategies .....	16
	Early Intervention Demands .....	16
	Team Approach to Treatment.....	18
	Occupational Therapy .....	18
	Occupational Therapy Theory .....	20
	Occupational Therapy Related Interventions.....	23
	Physical Activity.....	23

	Energy Conservation Techniques.....	24
	Utilizing Inventories .....	26
	Conclusion .....	26
III.	METHODOLOGY .....	28
IV.	PRODUCT .....	31
V.	SUMMARY .....	69
	REFERENCES.....	71

## CHAPTER I

### INTRODUCTION

Multiple Sclerosis (MS) is a neurological disease that can cause a variety of symptoms, including: fatigue, weakness, spasticity, balance problems, bladder and bowel problems, numbness, vision loss, tremors and depression. The progressive disease is known to cause severe disability in young adults. However, with the administration of medication combined with therapy, many MS clients can lead normal and productive lives. Unfortunately, most people who receive therapy for MS have been referred only after becoming severely disabled and are less likely to be successful in meeting rehabilitation goals. Therefore, early intervention is crucial for individuals inflicted with MS, and education of available early intervention techniques is vital.

Rehabilitation addresses many issues and challenges experienced by individuals with MS. Occupational therapists (OT's) are often utilized to complete therapy programs with these patients, because their training and clinical knowledge is directly congruent with the majority of MS symptoms. Occupational therapists work largely with the upper extremities and fine-motor control, but also encompass cognitive abilities and assist with fatigue management, energy conservation, and safety. The primary concern of OT is how individuals occupy their time and how they function in those occupations that are meaningful to them (Courtney & Lucuski, 2004).

Most individuals diagnosed with MS exhibit parallel symptoms, but the most common and pervasive symptom is fatigue (Trombly & Radomski, 2002). More than 80% of people with MS experience a worsening of symptoms with heat. It has been found that the use of cooling devices combined with exercise may help stave off various MS symptoms (Holzman, 2003). By developing a protocol for fatigue management, MS patients may experience a decrease in the progression rate of certain symptoms and an increase in quality of life. The proposed protocol will target those in the early stages of MS and will include implementing an exercise program that increases musculoskeletal strength, utilization of various energy conservation techniques, application of cold therapy (when necessary), and monitoring symptoms with correlating inventories.

To assist in the development of an early intervention guide for MS patients, the Biomechanical and Occupational Adaptation (OA) Models will be utilized. The Biomechanical Model will help to address the neurological and musculoskeletal characteristics associated with MS, while the OA Model will help to concentrate on making modifications to activities of daily living (ADLs). An extensive literature review will be conducted to support all methodology used in this scholarly project.

The overall goal of this project is to improve the quality of life for MS patients, while helping preserve their independence and safety by decreasing the severity of their symptoms. Using the frames of reference described above, the protocol will target fatigue management in the performance of ADLs. In addition, a guidance tool in the form of a booklet will be created to give to the client, family members, and/or caregivers. It is hoped that this protocol will effectively manage fatigue and increase or preserve gross motor skills in those inflicted with MS.

## CHAPTER II

### REVIEW OF LITERATURE

#### Description of Multiple Sclerosis

Multiple sclerosis is one of the most common neurological disorders known today; over 2,500,000 people around the world are inflicted with this disease. Multiple Sclerosis is the result of damage to myelin, a protective sheath surrounding nerve fibers of the central nervous system (CNS). Myelin is a fatty material that insulates nerves, allowing impulses to transmit more rapidly. When myelin is damaged, this interferes with messages between the brain and other parts of the body. The demyelination associated with MS is accompanied by a disruption in the ability of the nerves to conduct electrical impulses to and from the brain and this produces the various symptoms of MS. The sites where myelin is lost (plaques or lesions) appear as hardened (scar) areas and are discovered at different times and in different areas of the brain and spinal cord. The term multiple sclerosis literally means “many scars” (Multiple Sclerosis International Federation (MSIF), 2004).

#### Etiology & Epidemiology

Multiple Sclerosis is responsible for the neurological disability of many young and middle-aged adults. Although the cause of MS is not known, researchers have focused their attention on the following areas as areas of concern, including: climate, age, genetics, immunology, and viruses. The mean age of onset for MS is 29 to 33 years, while the range of onset is extremely broad, beginning at 10 years and ending at 59 years (MSIF, 2004). However, diagnosis of

MS is generally between 20 and 40 years of age and women are two times as likely to be diagnosed with MS as men are (Porth, 2002). Although MS occurs worldwide, it is most common in Caucasian people of northern European origin and is extremely rare amongst those of Asian and African descent. Multiple sclerosis is also more prevalent in temperate regions of the world, such as northern Europe, southern Australia, and the middle regions of North America. Although a family history of MS increases the risk of acquiring the disease, the likelihood of someone inheriting all the genetic factors contributing to MS is only 2%-4% (National Multiple Sclerosis Society (NMSS), 2002).

It has also been contrived that MS may be the result of a virus, or other infectious agents, that trigger the autoimmune response related to this disorder. Since, viruses are strikingly similar to myelin proteins a compromised immune system would not be able to detect the difference between the two and would attack the body's own myelin (NMSS, 2002). Other possible triggers include trauma, stress, and intake of cow's milk in early infancy.

#### Types of Multiple Sclerosis

There are four types of MS, these include: relapsing-remitting MS (RRMS), primary progressive MS (PPMS), secondary progressive MS (SPMS), and progressive relapsing MS (PRMS). Clinicians often refer to 'Benign MS' as a fifth type of the disorder. This form of MS does not worsen with time and complete recovery is usually reached after one or two attacks. Benign MS can only be identified when there is minimal disability 10-15 years after onset and when initial diagnosis was relapsing-remitting MS (MSIF, 2004).

According to the National Multiple Sclerosis Society (2004), approximately 85% of people living with MS initially experience the relapsing-remitting form. To be

designated as an RRMS relapse, the exacerbation must last for more than 24 hours with two relapses spaced at least a month apart. Relapse rates range from 1.5-12 times per year and research indicates that most untreated patients recover within six weeks of an acute relapse. Pregnant women generally experience a reduction in relapses but become more susceptible to attack in the three to five months following delivery (NMSS, 2004).

Secondary progressive MS is the major progressive form of MS, and it initially presents like RRMS. Instead, however, the relapsing patient transitions into a progressive slowly worsening stage marked by continued, deteriorating neurological deficits. In order to accurately diagnosis SPMS, an observation period of six months or greater of this transition must occur. In established SPMS, relapses typically diminish in frequency and then stop, while progressive neurological decline continues. In addition up to 90% of previously diagnosed relapsing patients eventually become SPMS patients (NMSS, 2002).

Primary progressive MS is characterized by continual worsening from onset, without relapses. In late stages of the disease, loss of function can become severely disabling. In PRMS, there is continual deterioration from the onset of the disease, with the ensuing manifestation of relapses. Unlike RRMS, there is no correlating pattern of disability associated with the relapses and remissions.

The most common of these forms is SPMS which consists of 40% of the MS population, RRMS is the next most prevalent effecting 25% of those with MS, benign MS accounts for 20%, and PPMS encompasses the remaining 15% of people diagnosed with MS (MSIF, 2004).

### Diagnosing Multiple Sclerosis



Unlike many diseases, there is no definite positive or negative diagnostic test for MS and none of the tests available are 100% conclusive on their own. Instead a 'clinical diagnosis' is made by a doctor, which is comprised of observing a person's symptoms and ruling out other possibilities. Unfortunately, for 10% to 15% of people seeking medical assistance, a definite diagnosis is still not possible even after all the available tests have been carried out. However, in the vast majority of cases diagnosis is possible due to the ability of clinicians to rule out other serious causes of MS type symptoms by conducting periodic examinations and monitoring changes in a person's condition. The Multiple Sclerosis International Federation's International Medical and Scientific Board developed new MS diagnostic criteria to assist medical professionals in distinguishing between MS and other conditions that may present with similar symptoms. The new criteria allow MRI scanning results to be included in the diagnostic process so that it may be possible to diagnose MS when someone has had only one episode of symptoms (MSIF, 2004). The new criteria enable persons experiencing MS-like symptoms to be classified as having MS, possibly having MS, or not having MS.

Early stages of MS may be identified as having a history of vague symptoms, which may occur intermittently over an extended period of time and could often be attributed to a variety of other medical conditions. In addition, subjective symptoms are often difficult to communicate to doctors and other health care professionals, and as a result people with MS may be treated unsympathetically in the very early stages of diagnosis.

Even when 'classic' patterns of MS-type symptoms are apparent, the symptoms must still conform to the agreed upon criteria before a definite diagnosis of MS can be made by a doctor or neurologist. The criteria are that two different

areas of the CNS be affected, the effects must be experienced on at least two separate occasions and at least one month apart, and the person must be within the normal age range for the onset of MS (MSIF, 2004). Although a person may be diagnosed with MS on their first visit to a neurologist, the uncertainty of giving a definite diagnosis is very likely. Because of the difficulties surrounding accurate diagnosis of MS, many individuals are not diagnosed until the later stages of the disease and therefore do not receive needed therapy services in a timely manner.

#### Course & Prognosis of Multiple Sclerosis

Multiple sclerosis is not a fatal disease, but in severe cases may pose a risk for life-threatening complications. This disease shortens the average life span of those inflicted by about six years, and in nearly all cases, the negative emotional impact of this disease and its symptoms is considerable. It has been found that approximately 10% to 35% of patients have a very mild form MS, with little if any disability, no need for medication, and a normal life expectancy. Those who only demonstrate optic neuritis, and other symptoms that affect the senses, have a better outlook than if symptoms appear more widespread. Approximately 70% of people inflicted with MS will experience some degree of progression. Multiple sclerosis, however, can sometimes remain asymptomatic or become only mildly symptomatic even long after initial plaque formation.

Recent research suggests that MS progression to moderate disability is often very slow in persons with the relapsing-remitting type compared to those with the chronic progressive type. Once an individual reaches a certain level of disability, however, the disease then worsens at the same rate in patients with either form of the disease (NMSS, 2002). To prevent such progression of MS, it is vital that early

intervention strategies be employed and interventions continue throughout the course of the disease.

### Clinical Signs & Symptoms

The signs and symptoms of MS vary from person to person and usually take place before diagnosis. Early symptoms are usually the cause of doctor referral and in-turn diagnosis of MS. Early symptoms include: optic neuritis, fatigue, heaviness or clumsiness in the arms and legs, tingling sensations, poor coordination, and Lhermitte's sign. Lhermitte's sign is an electrical sensation that runs down the back and into the legs when bending the neck forward. As MS progresses over months, or even years, symptoms can occur in practically every region in the body.

Later symptoms may include: spasticity, imbalance and dizziness, tremors, facial pain, spasm-related symptoms, speech difficulties, difficulty swallowing, emotional mood swings, and problems in the gastrointestinal, urinary, and genital tracts (NMSS, 2002). According to the Multiple Sclerosis International Federation (2004) other common symptoms may include: blurred or double vision, involuntary rapid eye movement, total loss of sight, ataxia, vertigo, paraesthesia, burning sensations, muscle pain, sexual dysfunction, cognitive disturbances, hearing and speech deficits, and sensitivity to heat. In considering the implications of symptomology for participation in occupations, particular attention should be drawn to the impact of heat, fatigue, and muscle weakness on occupational performance.

#### *The Most Commonly Reported Symptoms*

Fatigue is one of the most common symptoms of MS, occurring in approximately 80% of those diagnosed with the disorder (NMMS, 2004). In addition, up to half of persons diagnosed with MS have reported fatigue as their most significant and troublesome symptom. Fatigue is generally defined as a tiredness or

lack of energy that is not congruent with one's activity level, and is also frequently present during inactivity (Hatzakis & Haselkorn, 2003). Schwid et al. (2002) defines fatigue as a state of reduced capacity following a period of mental or physical activity. In addition to the high frequency of MS related fatigue, it has also been found to be different from other types of fatigue (Vanage, Gilbertson, & Mathiowetz, 2003). Multiple sclerosis related fatigue typically occurs on a daily basis, may be present in the morning (even after a restful night's sleep), and worsens as the day progresses. It is more severe than normal fatigue, can be aggravated by heat and humidity, and tends to come on more easily and suddenly (NMSS, 2004). As a result, fatigue can impede an affected person's ability to fully engage in desired occupational performance and roles (Vanage et al., 2003). Activities of daily living (ADLs) are affected the most due to lack of efficiency and endurance of MS patients. In accordance, individuals with MS experiencing high levels of fatigue often report a lower overall quality of life.

Along with fatigue, depression and muscle weakness and atrophy are commonly reported symptoms of MS. Generally, these deficits are indicators of physical inactivity. Since MS sufferers often exhibit these problems from the disease itself, they are at a higher risk of being exposed to such deficits without leading sedentary lives. This increases the need for individuals with MS to become and stay physically active. Once physical activity is limited, the capacity to perform physical acts becomes diminished. For MS sufferers who may already have physical limitations, the effect of inactivity is even more significant. Ultimately, the results of inactivity compounded by unpredictable disease progression may contribute to less social interaction, depressed mood, and diminished general well being (Sutherland & Andersen, 2001).

### *Symptom Exacerbation*

“More than 80% of people with MS experience a worsening of symptoms with heat-such as blurred vision, weakness, and increased fatigue” (Holzman, 2003, p 3). Elevations in body temperature magnify alterations in signal conduction caused by damage to the myelin surrounding the nerve axon, which further compromises the thermoregulatory system. During physical activity, only 25% of the metabolic processes are actually converted into muscle contraction, the remaining 75% is released as heat (Baker, 1999). As a result, individuals with MS have continually been informed to avoid participation in exercise in order to minimize the risk of creating symptom exacerbations and signs of fatigue (Sutherland & Andersen, 2001).

Heat-related exacerbations have created barriers for persons with MS to participate in much needed physical activities, but engaging in such activities is the only way to improve heat tolerance. It has been found that heat-induced worsening is only transient, and that symptoms improve once body temperatures return to their normal levels. In addition, symptoms tend to improve dramatically for many people when body temperature is reduced to hypothermic levels (Baker, 1998). It has been discovered that wearing a cooling garment for 40-45 minutes leads to improved motor performance (Kinnman et al., 1999). By regulating body temperature via cooling therapy, it may be possible for heat-sensitive individuals with MS to exercise to their maximum, and regain the long-term benefits of exercise (Baker, 1999).

### *Intervention Strategies*

#### *Early Intervention Demands*

Early intervention is crucial in the successful management and treatment of MS. This may prove to be difficult because the course of MS may begin before an

individual realizes he/she has the disease. It is generally accepted that the onset and progression of MS occur before explicit clinical symptoms begin, and progression continues during periods of apparent remission. There is evidence, substantiated by MRI and pathologic analysis, that MS can cause axonal damage even when there are no noticeable signs or symptoms of the disease (Whitney, 2001). Due to these findings, physicians have made early intervention the standard of care for MS patients and have suggested that treatment be ongoing, even during apparent remissions. Not only is this the most recent standard of care, early intervention is extremely important for controlling progression rates of those diagnosed with MS.

Recent studies have shown that those who initiate therapies as well as drug interventions at onset are more likely to be classified more clinically stable in four to five years than those who initiate these treatments late or not at all. In accordance, individuals who participate in therapy on a regular basis tend to demonstrate less severe neurological symptoms (Prescott, 2003). Not only is it important to preserve future function, but early comprehensive rehabilitation also helps establish a functional base line for initiation of intervention strategies (LaBan et al., 1998).

Before designing a personalized treatment plan for someone with MS, it is important to collect pertinent medical information from the individual. Since it is essential that patients with MS be treated with medication in accordance with their therapies, each member of the treatment team should know the correlating medications. There are three immunomodulating agents approved in the United States for treatment of MS, as well as a recombinant interferon beta-1a agent (Rebif) available for use in Europe, Canada, and Australia. The three agents currently available in the United States for treatment of MS are interferon beta-1a (Avonex),

interferon beta-1b (Betaseron), and glatiramer acetate (Copaxone). According to Whitney (2001) clinical studies signify that all three of these agents are successful in reducing the frequency and severity of exacerbations and the development of brain lesions, as measured by MRI.

### *Team Approach to Treatment*

An interdisciplinary approach is typically utilized to treat MS patients, because each discipline is specialized in different areas corresponding to this population. Excluding the primary health care providers, a treatment team may include people from the following disciplines: occupational therapy (OT), physical therapy (PT), speech therapy, massage therapy, and vocational therapy. Health care facilities may differ in the specific use of disciplines, but the general areas addressed by each discipline are universal. While, PT's main objective is to help restore and maintain useful movement or function, speech therapy is specialized in improving communication skills in MS patients who have difficulty speaking because of weakness or lack of coordination of face and tongue muscles. Massage therapy is used to relax muscles, reduce stress, and relieve conditions exacerbated by muscle tension or other MS related symptoms. Vocational therapy specialists focus on retraining or using adaptations and accommodations on the job; they may work independently or in consultation with an OT (NMSS, 2004).

### *Occupational Therapy*

Occupational therapy (OT) is an ever-evolving discipline that utilizes components of human occupation to guide and construct an individualized service delivery model. The field of OT maintains a unique focus on occupation and daily life activities and, ultimately, the application of an intervention process that facilitates engagement in occupation to support participation in everyday life. To assist in

personalizing each intervention, occupational therapy practitioners engage clients in everyday life activities, or occupations, that are meaningful and purposeful to that person (American Occupational Therapy Association (AOTA), 2002).

The basis for all occupational therapy practice is to facilitate changes in client performance, which supports engagement in meaningful occupations that subsequently affect health, well-being, and life satisfaction. According to AOTA (2002), engagement in occupation promotes participation in context because the engagement is a result of self-choice, motivation, and meaning. Operating from a holistic viewpoint, OT supports that both the mind and the body are interconnected and that emotional and physical elements are equally important. Consequently, both the subjective and objective aspects of performance are considered when designing interventions.

When considering occupational performance, it is important to remember the broad range of human occupations and activities that make up peoples' lives. Such activities are placed into categories called areas of occupation, including: activities of daily living (ADLs), instrumental activities of daily living (IADLs), education, work, play, leisure, and social participation (AOTA, 2002). Determining performance in any of these areas of occupation requires history or knowledge of an individual's performance skills (what one does) and performance patterns (routines).

Typically the way in which one performs an activity or completes a daily routine is conditional and influenced by context. According to AOTA (2002), context is defined as a variety of interrelated circumstances within and surrounding a person, which manipulates performance. Contexts can be either internal or external and may include: cultural, physical, social, personal, spiritual, temporal, and virtual.



To further evaluate one's ability to perform specific occupations and develop a personalized treatment approach both activity demands and client factors must also be considered. To analyze activity demands a therapist must look at the client's abilities or skills and determine if they are able to meet the demands of the activity at hand. Relevance of the activity should also be carefully considered so that the client remains invested in their treatment. Other factors that reside within the client, or client factors, include a variety of physical, cognitive, and psychosocial issues that influence development and performance and how illness disability, and disease affect these factors (AOTA, 2002). Client factors may include body functions and/or body structures.

By addressing various elements of a person's life and incorporating purpose and meaning into treatment, OT is able to provide a client-centered service delivery model. In addition, the process of evaluating a client's occupational needs, problems, and concerns, helps achieve a better understanding of the individual. From the evaluation process, a unique and personalized intervention plan is developed as a collaborative effort between the client and therapist. The ultimate goal of OT is to facilitate success and reach desired outcomes in order to plan future actions of the client and evaluate the program (AOTA, 2002). In accomplishing this goal, OT as a profession utilizes a dynamic evaluation, intervention, and outcome process model.

### *Occupational Therapy Theory*

Occupational Adaptation (OA) is a model utilized to guide the process of occupational therapy services. It is a phenomenon in which a person and therapist work together to engage participation in activities within pertinent contexts, rather than the therapist directing the individual (Kramer, Hinojosa, & Royeen, 2003). It is

focused on delivering client-centered services while utilizing this collaborative treatment process between the client and therapist. Occupational Adaptation highlights all of the main points of OT while providing specific treatment guidelines. The model has four main concepts that help form these guidelines, they include: developing and utilizing readiness skills as a foundation for treatment; using adaptation as a tool for facilitating functional independence; focusing on occupations that are purposeful and meaningful to the client; and creating a therapeutic environment that will improve functional skill performance.

One of the most important concepts of OA is to develop and utilize readiness skills to adapt a specific physical context so that an individual can successfully perform a specific occupation (Crist, Royeen, & Schkade, 2000). Occupational Adaptation suggests that readiness skills be assessed, developed, and employed within the treatment program to provide the patient with the appropriate foundation for successful completion of preset goals and objectives. The development of readiness skills assists in controlling, maintaining, and improving functional performance skills. The Biomechanical frame of reference can be used to address readiness skills that are often an issue for clients with MS, including deficits in range of motion, strength, structural integrity and endurance and maintain function (Willard & Spackman, 1998). This frame of reference also emphasizes the reduction of physical limitations to increase the success of reaching a desired level of independence (Jackson & Schkade, 2000).

Adaptation is the trademark of OT as a profession, as well as the OA model. It is identified as a change in the functional state of a person as a result of movement toward relative mastery over occupational challenges. The OA model implies that an individual is able to overcome occupational challenges by integrating an internal

occupational adaptation process. This process becomes reflex-like once an individual learns to utilize appropriate readiness skills and adapt their environment for the sake of the occupation at hand.

According to OA, focusing on the performance of occupations that are important to the individual is vital to providing effective treatment interventions and increasing patient compliance. In addition to being meaningful, the occupation must be relevant and useful in everyday life in terms of function. If these criteria are met, a patient will learn to adapt certain occupations to increase personal functional performance; this can be done by making an occupation easier or more challenging. Effective OT services attempt to facilitate such processes, instead of focusing on discrete skill development.

Environment is the compilation of external factors, circumstances, objects, or conditions that surrounds an individual. It is thought of as the aggregate of social and cultural conditions that influence one's life (Trombly & Radomski, 2002). To be successful, an individual must be able to meet the demands of their environment, whether it be socially or vocationally. When an environmental barrier is present, adaptations must be made to facilitate functional independence and create a therapeutic environment.

Once a program has been developed and instituted based on the four main concepts of OA, an OT can begin to observe the way in which the patient utilizes the internal occupational adaptation process during various occupations. During this process the OT is looking for the overriding goal of OA, which is the development of relative mastery. This happens only when three objectives are met, these objectives are: effectiveness, efficiency, and satisfaction (Crist et al., 2000). Ideally, this is when the client is able to reach maximal occupational participation in society and

allow the individual's adaptive capacity to reach its most functional level (Kramer et al., 2003).

### *Occupational Therapy Related Interventions for MS*

During therapy the individual is encouraged to consider the readiness skills required to participate in a particular occupation, and the effects of the context on the quality of performance of the occupation. It is necessary to prepare for the spectrum of symptomatic possibilities experienced by an MS patient on a daily basis and plan treatment interventions accordingly. For example, when an individual with MS desires to dress himself, he might find that he lacks the strength or endurance to complete the task. If the client is not experiencing symptom exacerbation, exercise might then be used to preserve or improve strength or endurance, creating a foundation of readiness skills required for success in this area. If, however, the individual is experiencing increased fatigue and/or muscle weakness with such occupations, energy conservation techniques would be implemented. Energy conservation techniques grade down the expectations of the occupational challenge such that relative mastery is still possible. Finding the balance between facilitating physical activity or energy conservation techniques is the key concept in developing readiness skills.

### *Physical Activity*

It has been found that exercise increases physical functioning and psychological well being, as well as reducing anxiety and depression. However, the appropriateness of physical activity for people with MS largely depends on their psychological tolerance and their responses to exercise. The OA model requires that interventions encompassed by treatment plans only be utilized if there is a link between the primary occupational environment and roles that have meaning for the

individual (Crist et al., 2000). In addition, tolerance to such exercises in MS may be influenced by a number of factors relating to the disease, including: duration of illness, level of impairment, and limitations imposed by exacerbation of symptoms (Sutherland & Andersen, 2001).

Interventions that promote general health, improve energy levels and mental health, and foster social interactions in the presence of physical disability are beneficial for individuals with MS. According to O'Callaghan (2003), Butler (2002), and Crotzer (2001), adaptive Tai Chi, water aerobics, and yoga are the most beneficial exercise programs for persons with MS. Careful instruction on proper techniques is an important aspect regarding safety for such exercise programs. The program should include stretching and range of motion exercises, to prevent joint contractures, and focus on the improvement or preservation of muscle function. The patient should be educated on the relationship between exercise and function, as this is essential in being successful with an exercise program.

There are also, precautions that need to be taken to avoid excessive fatigue during physical activity. The intensity and frequency of exercise should be carefully monitored and body overheating should always be avoided (LaBan et al, 1998). An exercise program designed to target people in the early stages of MS should be completed several times a day for short amounts of time. This allows the person to obtain much needed exercise or aerobic workout without over heating or becoming too fatigued.

### *Energy Conservation Techniques*

For an individual with MS, instruction in energy conservation, work simplification, and ergonomic techniques might be included in all daily activities. According to the OA model, the overriding goal of therapy is to help the patient

become more adaptive by facilitating internal occupational adaptation processes (Crist et al., 2000). Learning to adapt more readily to their environment by utilizing specific energy conservation techniques initiates these internal processes. Vanage et al. (2003) suggest various advantageous energy conservation techniques to assist in reducing or managing fatigue in the daily lives of those with MS. These techniques include: learning the value of rest; budgeting and banking energy throughout the day; incorporating rest periods when necessary; learning to communicate personal needs to others; using good body mechanics and posture; using energy-efficient appliances and organizing stations of activity; separating fatiguing tasks into components; prioritizing and setting standards for activities; planning rest periods with self-care, productivity, and leisure activities so that a balance can be maintained; and reviewing energy conservation principles and setting short-term and long-term goals.

Patients need to appreciate the importance of these energy saving techniques and use them readily. The family also should be instructed on these techniques and requested to encourage the patient to delegate tasks when needed. A shared, preplanned, and well-organized task is the best way to conserve energy (LaBan et al., 1998).

Occupational therapists may also suggest assistive devices to aid in ADL completion, such as: dressing and bathing aids, rocker knives, pot and pan stabilizers, and special grips for pens and pencils. Such modifications can be made to increase independence and to readily conserve much needed energy. There is an endless list of possible assistive devices that can be used for MS patients and new ideas or inventions are also an option.

### *Utilizing Inventories*

An important aspect of the OA frame of reference is the engagement of the patient in the treatment planning, as well as in the evaluation process (Crist et al., 2000). Using scales or inventories is one way of keeping track of physical and psychological changes and evaluating improvement or deterioration. For clients with MS, Schwid et al. (2002) offers a variety of tools utilized to monitor fatigue, including: Fatigue Assessment Instrument (FAI), Fatigue Impact Scale (FIS), Fatigue Severity Scale, and the Chalder Fatigue Scale (CFS). Each scale differs in the format and their manner of seeking appropriate responses from users. Regardless of which is utilized, these self-report questionnaires allow the user to provide an individualized response.

Utilizing the previous intervention strategies in the early stages of MS will assist in maintaining or improving an individual's current level of function. In conjunction, the Biomechanical and Occupational Adaptation frames of reference should be used to help guide the treatment. If used correctly, the Biomechanical model can enable a patient to overcome deficits and build on existing strengths (Jackson & Schkade, 2000). The OA model can be used to alter occupations, so that they are viewed from a non-traditional perspective and can become more client centered. In addition, the OA frame of reference will ensure that each intervention focuses on the enhancement of a process, not a discrete skill (Crist et al., 2000). Together these models can successfully target the needs of those diagnosed with MS and create a more appropriate and individualized treatment plan.

### **Conclusion: Project Need**

The literature demonstrates that there is a need for intervention programs which address the symptoms experienced by the MS patient early in their disease.

Active engagement in therapy may improve their functional capacity and provide personal investment into each treatment session. This can be accomplished most readily if it is a part of their daily routine. Using the OA model, one can conceptualize that individuals need a combination of readiness skills, environmental adaptations, and activity alterations to successfully manage the emerging symptoms of MS.

The project proposed is a mechanism that will assist the individual at home to maintain the readiness skills needed for participation in valued occupations, provide information regarding environmental adaptations and activity adaptations, and incorporate a process for self monitoring; which will increase awareness of progress and the need for environmental, activity, or skills intervention.

In order to successfully treat and manage MS and related symptoms using these mechanisms, an individualized treatment plan must be developed early in the course of the disease by the therapy team. Recent research findings suggest that it is beneficial for the majority of patients to address fatigue and muscle weakness. This theory supports the principles presented in the correlating guide for early intervention with MS patients, in that a combination of cold therapy, an exercise program, and fatigue management techniques have been developed to best treat this population universally.



### CHAPTER III

#### METHODOLOGY

In order to develop an effective treatment guide for the early intervention with MS patients a thorough literature review was conducted on the epidemiology/etiology of Multiple Sclerosis (MS) and current treatments utilized across therapeutic disciplines. The literature revealed that most people who receive therapy for MS have been referred only after becoming severely disabled and are therefore less likely to be successful in meeting rehabilitation goals and maintaining functional independence. A guide for early intervention, which focused on strength maintenance and fatigue management, was created for MS patients to use at home under the supervision of an Occupational Therapist (OT).

The guide targets those in the early stages of the disease because immediate initiation of therapeutic interventions and proper education of available intervention techniques is vital for long term functional independence. Specific focus was placed on adapting activities of daily living to provide fatigue management and musculoskeletal strengthening, with hopes of improving occupational outcomes.

The Biomechanical and Occupational Adaptation (OA) Models were utilized to assist in the development of this protocol. The Biomechanical Model was utilized to address the neurological and musculoskeletal characteristics associated with MS, while the OA Model provided the framework for making modifications to activities of daily living (ADLs).

The guide is organized by the varying need for either energy conservation techniques or muscle strengthening during ADL completion. The literature suggests that strength and endurance are ongoing issues for individuals with MS (LaBan et al., 1998). The guide therefore provides mechanisms for individuals to build strength and endurance in the context of performing everyday activities of daily living such as bathing, dressing, and bed mobility. In addition, the literature suggests that fatigue management skills are necessary and helpful to individuals with MS, as fatigue might also lead to further debilitation. In addition, the guide provides a specific mechanism for individuals to monitor their fatigue, and suggests specific adaptations of activities should fatigue be an issue. Because of the influence of heat on fatigue, specific mechanisms were built into the guide whereby individuals could closely monitor and decrease their exposure to heat or overheating in the context of ADL performance (Baker, 1999).

The *Guide for Early Intervention with MS Patients* is designed to target recently diagnosed MS patients or those in the early stages of the disease. It is a compilation of inventories, protocols, and helpful hints to enable patients to better understand MS and effectively manage associated symptoms. By regularly completing the enclosed exercises and stretches and following the correlating suggestions, those in the early stages of MS may slow the progression of the disease considerably.

This guide is an occupation based home program specifically designed for newly diagnosed MS patients. It is not intended to treat all types of MS. To ensure personal safety, the exercises should be reviewed with a certified occupational therapist (OT) before completing them independently. To be effective, the methods must be carried out regularly, as should the corresponding inventories. Doing so will

help indicate patterns of fatigue and target the causes associated with this symptom so that energy conservation techniques can be effectively utilized.

The ultimate goal of this product is to provide newly diagnosed MS patients with possible therapeutic and advantageous information so that they feel in more in control of their disease process. This manual will be a tool for individuals with MS, their caregivers, and family members to improve quality of life through the preservation of strength and endurance and effective fatigue management.

## CHAPTER IV

### PRODUCT

This chapter is intended to display and explain the focus of the scholarly project, a guide for the early intervention with patients diagnosed with Multiple Sclerosis. The purpose and description of the guide are included in the introduction portion of the product, in addition explicit instructions and pictures demonstrating various techniques involved in the program are displayed within the guide. In it's entirety, the following product serves as a convenient, easy to follow home program that should be administered under the care of an occupational therapist.

## *Introduction*

The *Guide for Early Intervention with MS Patients* is designed to target recently diagnosed multiple sclerosis (MS) patients or those in the early stages of the disease. It is a compilation of inventories, protocols, and helpful hints, whose purpose is to educate patients so they may better understand MS and effectively manage associated symptoms. By regularly completing the enclosed exercises and stretches and following the correlating suggestions, those in the early stages of MS may help slow the progression of the disease.

Multiple Sclerosis is a neurological disease that can cause various debilitating physiological symptoms. Spasticity, muscle atrophy, and fatigue are three of the most common symptoms that present themselves early in the course of MS. Spasticity is a motor disorder that causes muscle tightness or stiffness and can make movement, especially of the arms and legs, difficult (Medtronic, 2004). Muscle atrophy is the loss of muscle tissue that can result from the disease itself or from lack of physical activity. Fatigue is generally defined as tiredness and decreased energy level that is out of proportion to activity level and is also frequently present during inactivity (Hatzakis et al., 2003). It has been found that light aerobic exercise and stretching helps prevent or limit the onset of these symptoms. If left untreated, symptoms worsen and can result in loss of independence in many areas of life, such as activities of daily living (ADLs).

Activities of daily living include activities that are oriented toward taking care of one's own body, such as: bathing, showering, bowel and bladder management, dressing, eating, feeding, functional mobility, personal device care, personal hygiene and grooming, sexual activity, sleep/rest, and toilet hygiene (American Occupational



# GUIDE FOR EARLY INTERVENTION WITH MULTIPLE SCLEROSIS PATIENTS

**Developed by: Anni Stafford**

Advisor: Deb Byram

Therapy Association, 2003). Occupational therapy (OT) is a profession that is directed towards addressing such issues. The occupational adaptation (OA) model is utilized by occupational therapists to develop client-centered treatments in which occupations that are meaningful to the individual are targeted. The MS patient is instructed on pertinent readiness skills that assist in overcoming occupational challenges by adapting the environment and the occupation itself. Within the environmental context, many adaptations can be made to grade the task at hand by increasing the difficulty or making it easier to complete. The goal of therapy is to enhance the internal occupational adaptation process so that the individual can recognize which adaptations are necessary at various points in time. Self monitoring is helpful in tracking performance levels and identifying symptom patterns.

The collection of adaptations provided in the correlating guide is designed to challenge MS patients, so that they may improve functional independence and develop relative mastery of meaningful ADLs. There is an alternative tract to follow when MS-related symptoms are present; this tract provides energy conservation techniques so that ADL completion is less physically taxing. The early intervention guide is an occupation based home program specifically developed for persons with MS. It is not intended to treat all types of MS, and to ensure personal safety, the recommended exercises and techniques should be reviewed with a certified occupational therapist before completing them on your own. To be effective, the methods must be carried out regularly, as should the corresponding inventories. The inventories will help indicate patterns of fatigue and target the causes associated with their symptoms, so that energy conservation techniques can be effectively utilized and a personalized routine can be developed. Inventory results should be reviewed weekly with an occupational therapist, so that appropriate

adaptations can be made and emerging concerns can be addressed.

In addition to conforming to ADL adaptations recommended in the guide, MS patients should follow general guidelines to improving other areas of occupation.

There are many guiding principles that are available to manage MS-related symptoms, some of these include:

- Stay physically active. The most beneficial exercises for MS patients are those that encourage light aerobic exercise and include stretching, such as:
  - Tai Chi
  - Yoga
  - Water Aerobics
- Exercise for less amounts of time and increase your daily/weekly sessions. This helps avoid overheating and allows your body to be exposed to required physical activities.
- Use cooling suits/vests when exercising. This can help keep your body temperature from rising and allow you to be more physically active.
- Stay indoors or in a cooled environment when possible.
- Balance rest and exercise adequately. Too much activity will decrease your energy level, as will too little.
- Stay hydrated by drinking lots of water. This will increase your energy level and keep your body healthy.
- Eat nutritious foods and stay away from caffeine, alcohol, and tobacco products. MS sufferers are already prone to disability, don't add to the process.



- To effectively manage stress, develop a support group. This should consist of a group of people who you trust and feel comfortable talking to. You may want to join an MS support group, so that you can relate to them and vice versa.
- Stay active in your favorite leisure activities. If they are becoming difficult to complete, see your occupational therapist and adapt the activities so that you can still participate in them.
- Stay in control of your disease process as much as possible. Take proper medications and complete your home program so that you feel proactive; this will help manage stress levels.
- See a counselor if necessary. Nothing is wrong with seeking professional help for managing stress levels. It is better to ask for help than to become overwhelmed by life stressors.
- Seek Allied Health assessments and treatments. Obtaining a specialized treatment team can only better your chances of successfully managing MS symptoms. Contact your health professional as soon as a new symptom arises.

The goal of this product is to provide avenues for newly diagnosed patients to explore. This simple and easy to follow program allows users to remain within the privacy of their own home while utilizing therapeutic and advantageous information; which allows them to feel more in control of their disease process. By developing the foundation of occupational adaptation and managing MS-related symptoms more effectively, patient satisfaction is increased and so is their quality of life.

## *Challenging Your ADLs*

The following exercise guide is designed to increase activity level during ADL completion, in order to maintain and improve muscle strength, flexibility, and effectively manage fatigue levels. The exercises and stretches demonstrated are intended to provide physical functioning that may help keep a person with MS in shape without raising core body temperature. It is a guide to quick and easy exercises and stretches that can be completed in short sporadic intervals throughout a typical day. Each individual using this guide may adapt the exercises to better fit their functioning level. Increase or decrease repetitions as necessary, but do not over exert.

If you tend to overheat easily, you may want to wear a cooling device during the exercise activities.

\*Possible Cooling Devices Include: cooling vests, cooling body suits, cooling neck wraps, cooling suits with hoods, cooling caps

\*These may be worn during exercise or any time of the day when you feel overheated. Keeping your core body temperature down helps prevent increased fatigue levels. Those who suffer from heat-induced MS exacerbations should consider the use of cooling devices.

Use the weekly ADL Inventory and the Fatigue Management Inventory (FMI) to identify if you were challenged enough during your ADL completion, or if you require more activity. This will help identify a pattern of fatigue presence and target the causes.

## *Bed Mobility Exercises/Stretches*

**Figures 1-4;** There are many stretches that you can do to promote flexibility and maintain muscle strength before getting out of bed in the morning. Try the following:



**Figure 1**

**Figure 1:** Point your toes towards the opposite wall until you feel a good stretch in your legs; hold this position for 10 seconds. Relax for 5 seconds and repeat this stretch.

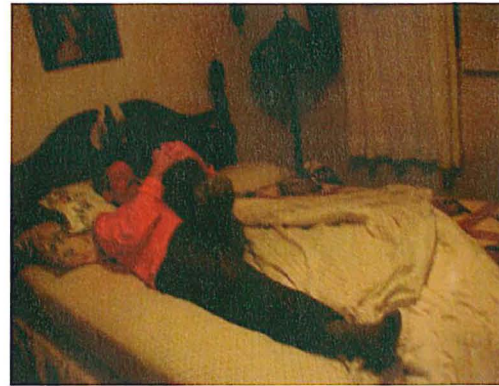


**Figure 2**

**Figure 2:** Pull your toes back towards your chin until you feel a good stretch in the back of your legs; hold this position for 10 seconds. Relax for 5 seconds and repeat this stretch.



**Figure 3.1**



**Figure 3.2**

**Figure 3.1 & 3.2:** Bring both knees to your chest (you may wrap your arms around your legs if desired) and hold this position for 10 seconds. Let one leg down (still keeping the other leg pulled toward your chest) and hold this position for 10 seconds, repeat this stretch with your other leg.



**Figure 4**

**Figure 4:** Bridge your back so that your stomach is moving toward the ceiling and most of your weight is on your shoulders, when you feel a good stretch in your back hold the position for 10 seconds. Relax for 5 seconds and repeat the stretch.



## *Edge of Bed Stretches*

**Figures 5-8;** After completing the previous stretches, slowly come to a sitting position. Once you have gained your balance on the edge of the bed straighten your back and put your feet flat on the floor, while maintaining good posture try the following neck stretches:



**Figure 5.1**



**Figure 5.2**

**Figure 5.1 & 5.2:** Drop your chin towards your chest and slowly roll your neck from side to side and then back, as if you were trying to make a circle in a clockwise direction. Once you have made 5 circles repeat the sequence, this time going in a counterclockwise direction.



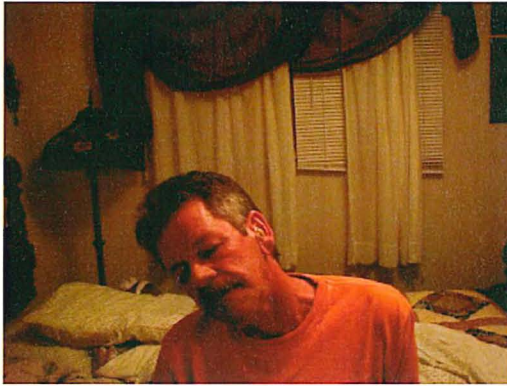
**Figure 6**

**Figure 6:** Put your chin on your chest until you feel a good stretch in the back of your neck and hold this position for 10 seconds. Relax for 5 seconds and repeat the stretch.



**Figure 7**

**Figure 7:** Point your chin to the ceiling until you feel a good stretch in the front of your neck and hold this position for 10 seconds. Relax for 5 seconds and repeat the stretch.



**Figure 8.1**

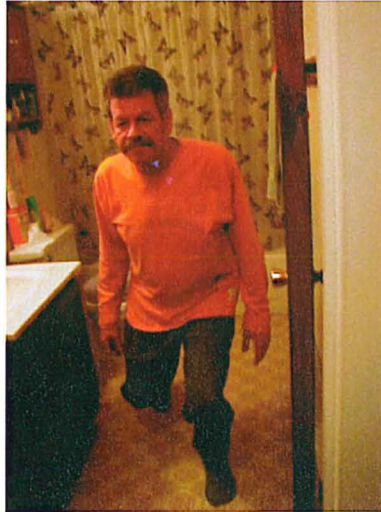


**Figure 8.2**

**Figure 8.1 & 8.2:** Bring your right ear to your right shoulder until you feel a good stretch on the left side of your neck, hold this position for 10 seconds (do not shrug your shoulders). Repeat on the other side (i.e. bring your left ear to your left shoulder, etc.).

## *Shower Routine Exercises/Stretches*

**Figures 9-12; While completing your shower routine, try these simple exercises and stretches (always demonstrate appropriate safety awareness):**



**Figure 9.1**



**Figure 9.2**

**Figure 9.1 & 9.2:** Before getting undressed, do some lunges. Stand shoulder width apart, place your left leg out in front of your right and slowly lower your upper body towards the floor by bending at the knees. Come down until your right knee touches the floor (your left knee should be directly over your left foot, creating a 90° angle). Slowly stand, straightening your legs out. Do this 10 times and repeat with the other leg.





**Figure 10**

**Figure 10:** While washing your lower body in the shower, stand with your feet together and wash towards your toes (bending at the waist and keeping your legs as straight as possible), once you reach your toes (or feel a tightening in the back of your legs) hold this position for 10 seconds. Relax for 5 seconds and repeat this stretch.



**Figure 11**

**Figure 11:** Grab your washcloth by both ends with both of your hands, slowly wring the wash cloth without moving the position of your hands. Once you feel a good stretch in your wrists stop and slowly ring in the opposite direction. Do this 10-15 times in each direction.



**Figure 12**

**Figure 12:** While rinsing off swing one arm behind you and step toward the wall, hold your arm against the wall of the shower. Hold for 10 seconds and repeat on other arm (you may move closer to the wall for a bigger stretch).

## *Towel Exercises:*

**Figures 13-16; Take advantage of drying off by following these simple towel exercises (demonstrate appropriate safety awareness):**



**Figure13.1**



**Figure 13.2**

**Figure 13.1 & 13.2:** Roll your towel and hold it out in front of you with both hands shoulder width apart, slowly raise towel above your head and towards the wall behind you until you feel a good stretch. Once you reach this point stop and slowly bring your arms back down to resting position. Do this 10-15 times.



**Figure 14.1**



**Figure 14.2**

**Figure 14.1 & 14.2:** Hold one end of the towel in your right hand and raise it above your head, let the other end fall down your back, reach behind your lower back with your left hand and grasp the other end of the towel. Pull upward with right hand until you feel a good stretch; hold this position for 10 seconds. Pull downward with your left hand until you feel a good stretch, hold this position for 10 seconds. Repeat by reversing right and left hand positions on the towel.





**Figure 15**

**Figure 15:** Sit on the floor and hold the towel at both ends with both hands, loop towel around your feet and lift your heels off the ground keeping your knees straight (to lighten the load on your legs being used, pull more with your arms) do this 10-15 times.



**Figure 16.1**



**Figure 16.2**

**Figure 16.1 & 16.2:** Sit on a chair or toilet and place your towel flat on the floor in front of your feet. Place one foot on the edge of the flat towel and grab the towel repeatedly with your toes (slowly moving the towel towards you). Keep doing this until the other end of the towel is at your toes. Reverse so that you are slowly flattening the towel out again. Repeat with other foot.

## *Dressing Exercises/Stretches*

**Figures 17-20; Challenge yourself while getting dressed by trying the following exercises and stretches:**



**Figure 17**

**Figure 17:** When putting your socks on stretch your leg out straight in front or to the side of you and bend from the waist to apply sock (keeping your knee as straight as possible). Once your sock is on, hold your position for 10 seconds. Repeat on your other leg.



**Figure 18.1**



**Figure 18.2**

**Figure 18.1 & 18.2:** Stand on the tips of your toes when pulling up your pants, once you've finished buttoning and zipping hold your position for 10 seconds. Flatten your feet and bend at the knees (go down as far as you can) and hold for 10 seconds.



**Figure 19**

**Figure 19:** If you have a belt (tie, scarf, etc.) place both hands behind your back and grab the ends of the belt. Pull up until you feel a stretch, hold this position for 10 seconds. Relax for 5 seconds and repeat the stretch.



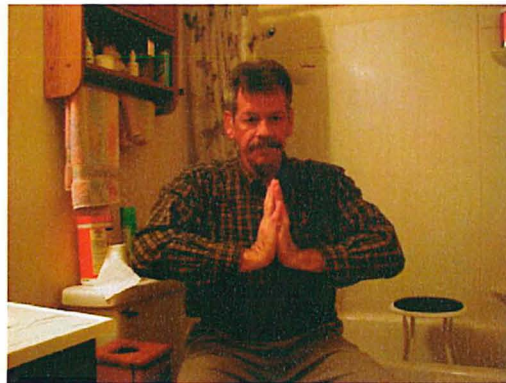
**Figure 20**

**Figure 20:** Once you are dressed and your shoes are on, jog in place for 30 seconds. Relax for 15 seconds (take a drink of cold water if necessary) and repeat. Stop and do not repeat if you are feeling overheated at any time.



## *Daily Routine Exercises/Stretches*

**Figures 21-24;** There are several exercises and stretches you can do throughout the day that aren't time consuming and will help to keep your muscles in shape. Try these during a break:



**Figure 21**

**Figure 21:** While using the restroom give your wrists a stretch by placing your palms together (in a praying position), keep your elbows parallel to the floor. Slowly raise your elbows until you feel a good stretch, hold this position for 10 seconds. Repeat this stretch 3 times, relaxing for 5 seconds in between each stretch.



**Figure 22**

**Figure 22:** While sitting in a chair, place your hands on the seat by your thighs and lift your body weight off of the chair, do this 10-15 times.



**Figure 23**

**Figure 23:** While brushing your teeth or grooming, balance on one leg to complete the task; balance for 10-15 seconds and repeat with other leg.



**Figure 24**

**Figure 24:** Before sitting to eat breakfast, lunch, or dinner, place your back against a wall and slide your bottom towards the floor (keep your thighs parallel to the ground and keep knees bent at a 90° angle) hold in this position for 20-30 seconds. Stop immediately if you begin to feel overheated.

## *Bedtime Stretches and Relaxation Techniques*

**Figures 25-28;** Before going to bed give your muscles a stretch and then relax them, so that you don't have any stored tension. Try the following:



**Figure 25**

**Figure 25:** Stretch your calf muscles by placing your foot on the wall and pushing your heel down to the floor, hold this position for 10 seconds and repeat on other foot.



**Figure 26**

**Figure 26:** Sit in bed with your knees bent and pointing outward (the bottoms of your feet should be touching), push the outside of your knees towards the bed until you feel a good stretch, hold this position for 10-15 seconds.





**Figure 27**

**Figure 27:** Once you are lying in bed, do a full body stretch by pushing your arms towards the headboard and stretching your feet towards the footboard of your bed; hold this stretch for 10-15 seconds.



**Figure 28**

**Figure 28:** Before going to sleep, relax your body and all of your muscles (if something feels tense shake it gently and envision complete relaxation). Close your eyes and take 10 deep breaths (breathe in through your nose and out through your mouth).

## *Energy Conservation within ADLs*

The following information is intended to decrease the amount of physical output by an MS patient during ADL completion, so that energy may be conserved for disbursement throughout the duration of each day. Although it is advantageous to challenge yourself during ADL completion, it is detrimental when one is experiencing increased fatigue. When fatigue is present, it is necessary to take precautions to conserve energy so that it is possible for the individual to successfully complete day to day activities. There are many energy conservation techniques that can be utilized when performing ADLs. The following guide exhibits a few helpful ways to conserve energy while performing ADLs.

## *Bed Mobility/Sleeping Patterns*

**Techniques 1-3;** There are many techniques that can be utilized to conserve energy in regards to bed mobility. To reduce the level of difficulty in this area, eliminate unnecessary movements by trying the following:

**Technique 1:** Place blocks under your bed frame to raise your bed to a level that requires less effort to get in or out of the bed. Making the bed too high or too low will require more effort on your part; the height of the bed should be 3-4 inches below your buttocks. Heights may vary from person to person depending upon preference and what works best for that individual.

**Technique 2:** In order to exert less energy when going to bed or getting up, you should sleep on the side of the bed closest to the door. This will require less distance to cover and make a difference in total daily energy expenditure.

**Technique 3:** In order to keep your energy level high throughout the day, you must get adequate sleep at night. Too much or too little sleep can cause decreases in your energy level; a restful night's sleep includes 6-8 hours of continuous rest. If you feel fatigued during the day, give your energy a boost by taking a nap for 30-60 minutes. Listen to your body as to how many naps per day that you require.

## *Shower Routine*

**Techniques 4-7:** To avoid using too much energy during your shower routine, try the following tips:

**Technique 4:** Complete your showering routine in a sequence of 3 steps; this requires less movement and allows you to take frequent breaks.

- Undress (take a break)
- Shower while sitting then get out (take a break)
- Dress yourself (take a break)

**Technique 5:** If necessary, use adaptive equipment when showering. This makes the task easier and requires less energy to complete the whole process. Try using a shower chair and a hand-held showerhead so that you may sit to take your shower. You may also use a long-handled sponge and grab bars to assist you in the shower. Grab bars should be placed at elbow height so that they may be accessed more conveniently.

**Technique 6:** Keep water temperatures low. Too much heat increases fatigue in MS patients. Taking cool/warm showers helps store energy so that it can be used more efficiently later in the day.

**Technique 7:** Remain sitting to dry off. You may do this in or out of the shower, but make sure to dry off enough to prevent slipping when getting out.



## *Dressing Routine*

**Techniques 8-11:** When performing your daily dressing routine, plan ahead and use energy saving techniques. The following can help conserve energy:

**Technique 8:** If you have more energy at night time, lay out your clothes for the next day (if not do it in the morning). Place your clothes in a chair by the bed/shower so that they may be easily accessed. This will prevent you from having to run from room to room during your dressing routine.

**Technique 9:** Sit to get dressed and complete your dressing in a sequenced manner that saves you energy. First, dress your upper body, and then start all your lower body dressing before standing. For example, place your undergarments and pants on your legs, pull them to your thighs but don't stand up yet, put on your socks and shoes, then stand up and pull up your underwear and pants. This sequencing pattern prevents you from standing and sitting multiple times.

**Technique 10:** Place clothes hampers in each room. This prevents you from having to carry dirty clothes from one room to the next.

**Technique 11:** If necessary, use adaptive equipment to assist you in dressing tasks.

A reacher may be useful for grabbing items out of your reach and preventing you from repetitive standing. A long handled shoe horn may also prove useful in saving energy, because you don't have to bend as far to put on your shoes. Try not to use these unless you are experiencing fatigue, because relying on such aids at all times will decrease long term abilities.

## *Toilet Hygiene*

**Techniques 12-14: Simplify your bathroom routine by implementing these changes:**

**Technique 12:** Sit whenever toileting (for males). This will allow your muscles to rest instead of utilize energy required resist gravity during standing.

**Technique 13:** Use a raised toilet seat and grab bars to reduce the amount of energy it takes you to sit. The raised seat will require less distance to sit and the grab bars can help distribute the work evenly between your arms and legs, so one area is not getting overworked.

**Technique 14:** Keep necessary supplies close to the toilet in case you run out. Keep a small cupboard, fully stocked, next to the toilet. If you run out of an item, you can stay seated while retrieving more.

## *Grooming Tasks*

**Techniques 15-17:** To be efficient with grooming tasks, use equipment and rest breaks to help conserve your energy.

**Technique 15:** Sit to complete as many grooming tasks as possible. If you cannot sit for any reason, take frequent rest breaks.

**Technique 16:** Use adaptive equipment to exert less energy. An electric shaver can be used instead of a razor, an electric toothbrush instead of a standard toothbrush, and combs/brushes with long handles may replace your regular combs/brushes. These items can give you an extra advantage and require less energy to complete correlating tasks.

**Technique 17:** Place frequently used items in a convenient location. Also, keep such items together and close to where you will be using them. This will prevent you from having to retrieve items from various locations and saves you energy in the long run.

## *General Guidelines*

**Techniques 18-21:** There are some general guidelines that you can follow to conserve energy throughout the day. Some of these include:

**Technique 18:** Drink plenty of water (8-8 oz. glasses a day minimum). Dehydration causes increased fatigue levels and can cause other physiological problems.

**Technique 19:** Complete activities that require increased amounts of energy at peak times of the day. In other words, perform more difficult tasks during the time of the day that you tend to experience a higher energy level.

**Technique 20:** Slide heavy objects across counter surfaces instead of carrying them. Sliding an object is less physically straining than carrying it, because the weight of the object is distributed between you and the counter.

**Technique 21:** Prepare pre-cooked meals that require heating using an oven, microwave, or stovetop. This will reduce the number of steps required to make a full meal.

## *Fatigue Management Inventory*

The Fatigue Management Inventory (FMI) is an evaluation tool designed for monitoring the fatigue levels of people recently diagnosed with Multiple Sclerosis (MS). The FMI is intended to monitor fatigue progression on a weekly basis in order to identify possible patterns associated to increased fatigue levels. The inventory should be completed each week on the same day to promote consistency and reliability.

Read each statement and assign a value that accurately reflects your fatigue level during the past week. A low value (1) means you never experienced what the statement is implying, whereas a high value (5) indicates that you always experienced this aspect throughout the past week. It is possible to fluctuate between these values; a middle score should be assigned in such cases. Total your scores and keep each inventory for comparison purposes.

**Week of:** \_\_\_\_\_

Never  $\longleftrightarrow$  Always

1. My fatigue level has increased during the morning hours..... 1 2 3 4 5
2. My fatigue level has increased during the afternoon and evening hours ..... 1 2 3 4 5
3. My fatigue level has increased after periods of physical activity..... 1 2 3 4 5
4. My fatigue level has increased after completion of my ADL routine..... 1 2 3 4 5
5. My fatigue level has Increased due to stressors at work or home..... 1 2 3 4 5
6. Due to increased fatigue levels my motivation has decreased ..... 1 2 3 4 5
7. My overall occupational performance has suffered due to increased fatigue levels..... 1 2 3 4 5

**TOTAL** \_\_\_\_\_

## *ADL Performance Inventory*

The ADL (Activities of Daily Living) Performance Inventory is a checklist that targets specific areas of daily occupation that are affected by Multiple Sclerosis (MS). By using this inventory people with MS can observe their weekly performance in ADLs and better monitor disease progression. Complete the inventory weekly by checking the boxes that contain specific areas of concern. Give each category a performance rating value from 1-5 (1=performance not affected; 5=performance enabled). After completing the inventory, areas of concern should be addressed by the client and their occupational therapist (OT).

**Week of:** \_\_\_\_\_

**This week I have experienced difficulties in the following areas:**

### **ACTIVITIES OF DAILY LIVING**

#### **Bathing/Showering**

- ☐ Obtaining and Using Supplies
- ☐ Soaping, Rinsing, and Drying Body Parts
- ☐ Maintaining Bathing Position
- ☐ Transferring to/from Bathing Positions

**RATING** \_\_\_\_\_

#### **Bowel and Bladder Management**

- ☐ Control of Bowel Movements
- ☐ Control of Urinary Bladder
- ☐ Use of Equipment/Agents for Bladder Control

**RATING** \_\_\_\_\_

#### **Dressing**

- ☐ Selecting Clothing and Accessories
- ☐ Obtaining Clothing
- ☐ Dressing and Undressing
- ☐ Fastening/Adjusting Clothing and Shoes

**RATING** \_\_\_\_\_

#### **Eating**

- ☐ Manipulating Food/Fluid in Mouth

- ☐ Swallowing

**RATING** \_\_\_\_\_

#### **Feeding**

- ☐ Setting up Food/Drink
- ☐ Arranging Food/Drink
- ☐ Bringing from Plate/Cup to Mouth

**RATING** \_\_\_\_\_

#### **Functional Mobility**

- ☐ Moving from One Position to Another
- ☐ Bed/Wheelchair Mobility
- ☐ Transfers
- ☐ Functional Ambulation
- ☐ Transporting Objects

**RATING** \_\_\_\_\_

#### **Personal Device Care**

- ☐ Using Personal Care Items
- ☐ Cleaning/Maintaining Personal Care Items

**RATING** \_\_\_\_\_

**Personal Hygiene and Grooming**

- ☐ Obtaining and Using Supplies
- ☐ Removing Body Hair
- ☐ Applying/Removing Cosmetics
- ☐ Cleaning/Maintaining Hair
- ☐ Caring for Nails
- ☐ Caring for Skin/Ears/Eyes/Nose
- ☐ Applying Deodorant
- ☐ Cleaning Mouth
- ☐ Brushing and Flossing Teeth
- ☐ Maintaining Dental Orthotics/Prosthetics

**RATING** \_\_\_\_\_

**Sexual Activity**

- ☐ Engagement in Sexually Satisfying Activities

**RATING** \_\_\_\_\_

**Sleep/Rest**

- ☐ Maintaining Adequate Sleep/Rest

**RATING** \_\_\_\_\_

**Toilet Hygiene**

- ☐ Obtaining and Using Supplies
- ☐ Clothing Management
- ☐ Maintaining Toileting Position
- ☐ Cleaning Body

**RATING** \_\_\_\_\_

**COMMENTS:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



## *References*

- American Occupational Therapy Association. (2002). Occupational therapy practice framework: Domain and process. *American Journal of Occupational Therapy, 56*, 609-639.
- Hatzakis, M., Haselkorn, J., Williams, R., Turner A., & Nichol, P. (2003). Telemedicine and the delivery of health services to veterans with multiple sclerosis. *Journal of Rehabilitation Research & Development, 40*(3), 265-282.
- Medtronic. (2004). Spasticity: Take charge and understand your options. Retrieved October 29, 2004, from <http://www.medtronic.com/corporate/about.html>.

## CHAPTER V

### SUMMARY

The literature demonstrates that there is a need for intervention programs which address the symptoms experienced by the MS patient early in their disease. Active engagement in therapy may improve their functional capacity and provide personal investment into each treatment session. This can be accomplished most readily if it is a part of their daily routine. Using the Occupational Adaptation model, one can conceptualize that individuals need a combination of readiness skills, environmental adaptations, and activity alterations to successfully manage the emerging symptoms of MS.

The project proposed is a mechanism that will assist the individual at home to maintain the readiness skills needed for participation in valued occupations, provide information regarding environmental adaptations and activity adaptations, and incorporate a process for self monitoring; which will increase awareness of progress and the need for environmental, activity, or skills intervention.

In order to successfully treat and manage MS and related symptoms using these mechanisms, an individualized treatment plan must be developed early in the course of the disease by the therapy team. In adjunction to recent findings, it seems to be most beneficial for the majority of patients to address fatigue and muscle weakness. This theory supports the principles presented in the correlating guide for early intervention with MS patients, in that a combination of cold therapy, an exercise

program, and fatigue management techniques have been found to best treat this population universally.

To provide a convenient and effective guide for MS patients to use while in an everyday conventional setting, it is necessary to include both challenging and energy conserving techniques. This allows the individual to improve function while preserving quality of performance, if initiated at onset. This emphasizes the importance of immediate physician referral. In order to initiate an increase in physician referrals, it would be necessary to educate the medical profession on the benefits of such a program and make them aware that such a guide exists.

Not only is the guide effective for patients of the MS population, but also for those diagnosed with a variety of other disorders. The guide could be adapted to appropriately serve Individuals with any type of muscle weakness, extreme fatigue, and/or debilitating neurological disorders. It could also be used as a maintenance tool for older individuals, providing simple suggestions that could be used to improve function and preserve much needed energy. The mechanisms encompassed in the guide can be taught in a rehabilitation setting, on an out patient basis, or simply in the patient's home.

In order to distribute the guide in an effective manner, multiple copies would have to be made, and perhaps even a simplified and individualized version of the ADL exercises and energy conservation techniques. Such convenient packets could be available for those in need at doctor offices, clinics, or hospital lobbies.

Finally, It is recommended that research be conducted on the efficacy of these techniques in improving the quality of life and capacity for active engagement over the course of MS, and modifications made to further enhance the quality and applicability of the product.

## REFERENCES

- American Occupational Therapy Association (AOTA). (2002). Occupational therapy practice framework: Domain and process. *American Journal of Occupational Therapy*, 56, 609-639.
- Baker, D.G. (1999). Searching for ways to stay cool with MS. Retrieved September 7, 2004, from <http://www.mscares.org/msqr/summer99/page5.html>.
- Baker, D.G. (1998). Cooling: A simple therapeutic tool for multiple sclerosis. *Multiple Sclerosis Quarterly Report*, 17(4), 1-5.
- Butler, C. (2002). Walking in water. *Inside MS*, 20(3), 66-70.
- Courtney, S.W. & Lucuski, L.A. (2004). The benefits of rehabilitation. *MSAA Motivator (Winter)*, 7-24.
- Crist, P.A, Royeen, C.B., & Schkade, J.K. (2000). Infusing occupation into practice (2nd ed.). Bethesda: American Occupational Therapy Association.
- Crotzer, S. (2001). Welcome to the yoga jungle. *Inside MS*, 19(1), 54-56.
- Hatzakis, M., Haselkorn, J., Williams, R., Turner A., & Nichol, P. (2003). Telemedicine and the delivery of health services to veterans with multiple sclerosis. *Journal of Rehabilitation Research & Development*, 40(3), 265-282.

- Holzman, D. (2003). Keeping cool: Use of cooling devices helps keep MS symptoms at bay. *Multiple Sclerosis Outlook*, 3(2), 3-5.
- Jackson, J.P. & Schkade, J.K. (2001). Occupational adaptation model versus biomechanical rehabilitation model in the treatment of patients with hip fractures. *American Journal of Occupational Therapy*, 55(5), 531-537.
- Kramer, P., Hinojosa, J., & Royeen, P.B. (2003). Perspectives in human occupation: Participation in life. Philadelphia: Lippincott Williams & Wilkins.
- LaBan, M.M., Martin, T., Pechure, J., & Sarnacki, S. (1998). Physical and occupational therapy in the treatment of patients with multiple sclerosis. *Physical Medicine and Rehabilitation Clinics of North America*, 9(3), 603-614.
- Medtronic. (2004). Spasticity: Take charge and understand your options. Retrieved October 29, 2004, from <http://www.medtronic.com/corporate/about.html>.
- Multiple Sclerosis International Federation (MSIF). (2004). World of multiple sclerosis. Retrieved October 4, 2004, from [http://www.ifmss.org.uk/en/ms\\_the\\_disease.html](http://www.ifmss.org.uk/en/ms_the_disease.html).
- National Multiple Sclerosis Society (NMSS). (2002). Client programs: MS & exercise. Retrieved October 4, 2004, from <http://www.nationalmssociety.com>.
- National Multiple Sclerosis Society (NMSS). (2004). The MS information sourcebook. Retrieved September 7, 2004, from <http://www.nationalmssociety.org>.

- O'Callaghan, S. (2003). Adaptive tai chi. *Inside MS*, 21(3), 66-71.
- Porth, C.M. (2002). Pathophysiology: Concepts of altered health states (6<sup>th</sup> ed.). Philadelphia: Lippincott Williams & Wilkins.
- Prescott, B. (2003). Data supports extremely early intervention for multiple sclerosis. Retrieved September 7, 2004, from [http://bidmc.harvard.edu/tools/newsnow/pr\\_out.asp?pr\\_id=454](http://bidmc.harvard.edu/tools/newsnow/pr_out.asp?pr_id=454).
- Schwid, S.R., Covington, M., Segal, B.M., & Goodman, A.D. (2002). Fatigue in multiple sclerosis: Current understanding and future directions. *Journal of Rehabilitation Research and Development*, 39(2), 211-224.
- Sutherland, G. & Andersen, M.B. (2001). Exercise and multiple sclerosis: Physiological, psychological, and quality of life issues. *Journal of Sports Medicine and Physical Fitness*, 41(4), 421-433.
- Trombly, C.A. & Radomski, M.V. (2002). Occupational therapy for physical dysfunction (5th ed.). Philadelphia: Lippincott Williams & Wilkins.
- Vanage, S.M., Gilbertson, K.K., & Mathiowetz, V. (2003). Effects of an energy conservation course on fatigue impact for persons with progressive multiple sclerosis. *American Journal of Occupational Therapy*, 57(3), 315-323.
- Whitney, D.K. (2001). Early diagnosis and intervention in multiple sclerosis. *International Journal of MS Care*, 3(3), 1-11.
- Willard, H.S., & Spackman, C.S. (1998). Occupational therapy (9<sup>th</sup> ed.). Philadelphia: Lippincott Williams & Wilkins.